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Body Image in Burn Survivors

# From Survival to Socialization: A Longitudinal Study of Body Image in Survivors of Severe Burn Injury

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#### ABSTRACT

**Objective:** Little is known about the course of body image dissatisfaction following disfiguring injury or illness. The objective of this study was to test a proposed framework for understanding the trajectory of body image dissatisfaction among burn survivors and to longitudinally investigate the role of body image in overall psychosocial functioning.

**Methods**: A sample of 79 survivors of severe burn injuries completed the Satisfaction with Appearance Scale (SWAP), the Importance of Appearance subscale of the Multidimensional Body-Self Relations Questionnaire (MBSRQ-IA), and the SF-36 in the hospital and 6 and 12 months post-discharge (SWAP and SF-36). A repeated measures analysis of covariance model was used to assess the course of body image dissatisfaction over time, and a path analysis model tested the role of body image dissatisfaction in mediating the relationship between preburn and postburn psychosocial functioning.

**Results**: Female sex (p < .05), total body surface area (TBSA) burned (p < .01), and importance of appearance (p < .01) predicted body image dissatisfaction. From hospitalization to 12 months post-discharge, body image dissatisfaction increased for women (p < .01) and individuals with larger burns (p < .01) compared, respectively, to men and individuals with smaller burns. In the path analysis, body image dissatisfaction was the most salient predictor of psychosocial function at 12 months ( $\beta = .53$ , p < .01) and mediated the relationship between preburn and 12-month psychosocial function.

**Conclusion:** Findings from this study suggest the importance of routine psychological screening for body image distress during hospitalization and after discharge.

#### INTRODUCTION

Body image esteem or satisfaction is a multidimensional concept that relates to perceptions about one's physical appearance and the degree to which a person is satisfied with his or her appearance [1]. Concerns about physical appearance are of great import in a socio-cultural context that places a high premium on physical attractiveness, and perceived physical attractiveness is associated with many important personal characteristics and social advantages [2,3]. Studies have consistently found that attractive children and adults are judged and treated more positively than unattractive children and adults [2]. Attractive people are perceived to be healthier [4], more competent [3], to have more positive personality characteristics [3], and to be more likely to succeed academically [5] than unattractive people. They are more likely to receive help from strangers [6], are treated more leniently in judicial situations [7], and have a distinct advantage in hiring, promotion, and job performance evaluations [8].

People with visible disfigurement, on the other hand, report being confronted with frequent staring, audible comments about their appearance, unsolicited questions about the cause of their disfigurement, and other avoidant and stigmatizing behaviors [9-11]. *Acquired disfigurement* can result from trauma, disease processes, or surgical intervention [e.g., mastectomy] and often produces sudden and dramatic changes in one's appearance [9,12,13]. High levels of distress or dissatisfaction related to body image have been reported among people with acquired disfigurement related to conditions such as cancer [14,15], facial lacerations or fractures [16], scleroderma [17], vitiligo [18], psoriasis [19], and serious burn injury [12,20]. Higher body image dissatisfaction among patients with these conditions is associated with general psychological distress, poor self-esteem [21-23], symptoms of anxiety and depression *4* 

[9,17,21,22,24], including high levels of social anxiety [22], social isolation [25], and sexual problems [15].

A major burn injury can cause considerable damage to skin integrity and often leads to hypertrophic scarring. In addition to altering appearance, burns can impair physical function. Scars across joints, for example, can limit range of motion substantially [26]. Distress related to body image is a common problem among burn survivors even many years after the burn injury [12,20,27] and is associated with symptoms of depression and social difficulties [27,28]. Factors that have been related to high levels of body image dissatisfaction in burn injury include the severity of the disfigurement (e.g., extent or visibility of scarring) [12,27,29], female sex [27,29,30], and the degree to which physical attractiveness is valued [20].

Relatively little is known about the course of body image distress or dissatisfaction following disfiguring injury or illness, and only one study [31] has tracked body image concerns among patients with acquired disfigurements more than 1-2 months longitudinally from the time of disfigurement [13]. That study of 44 patients with oral and pharyngeal cancer who underwent free-flap reconstruction used a single questionnaire item to assess disfigurement concerns and reported a significant increase in distress compared to pre-surgery at 6 weeks, 3 months, 6 months, and 12 months post-surgery [31].

People with acquired disfigurement face the duel challenges of managing their own emotional response to disfigurement and dealing with the behavior of others [32]. Thompson et al. [33] described a period at the onset of vitiligo characterized by uncertainty and anxiety, a sense of difference, and a growing awareness of the social implications of disfigurement followed by a phase in which patients attempt to minimize their differences through avoidance of

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social situations or concealment of the disfigurement. A final stage described by Thompson is the development of a fragile sense of acceptance of the disease as uncontrollable, but not necessarily as overwhelming the individual's ability to cope. James Partridge, a burn survivor and founder of *Changing Faces*, a United Kingdom based advocacy and educational organization for people with disfigurement, has proposed that burn survivors move through similar stages [34]. According to Partridge's framework, the first months after the burn injury are characterized by survival, and the focus is on physical recovery and rehabilitation. Burn survivors at this stage are likely to be surrounded by supportive health professionals, family, or friends, and often maintain a preburn sense of self-concept. Key psychological issues include pain, grief, posttraumatic stress, and early appearance anxiety. As recovery progresses, typically by 6 months post-discharge, the level of professional and social support decreases and socialization becomes a central challenge. During this phase, which may last from several months to 2 years or more postburn, patients may shift between a preburn or temporarily scarred vision of the self and an identity as a person with a permanent disfigurement. Anger, shame about body image, and dysphoria are likely to be prominent issues in addition to ongoing grief and fear. Partridge also proposed a third stage, advocacy, in which survivors transform their sense of self through the adaptation of attitudes that are incompatible with society's idealization of "cosmetic purity" in order to rebuild a sense of self-esteem [34,35].

The objective of this study was to test whether body image worsens over the first year of burn recovery as suggested by both Thompson [33] and Partridge [34] by tracking the course of body image dissatisfaction longitudinally from the time of discharge from the index hospitalization (survival) to one year post-discharge (socialization) among a sample of survivors

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of serious burn injury. Specifically, it was hypothesized that body image dissatisfaction would increase significantly from discharge to one year post-discharge and would mediate the relationship between preburn psychosocial function and psychosocial function 12 months post-discharge. In addition, based on previous research on body image among burn survivors, it was hypothesized that body image dissatisfaction would be higher and increase more from baseline for female patients, patients with larger total body surface area (TBSA) burned, and for patients who valued physical appearance more highly.

#### METHOD

#### **Participants**

Study participants were patients with acute burn injury admitted to the Johns Hopkins Burn Center from January 1998 through October 2003. Patients were eligible for the study if they were 16 years or older and met one or more of the American Burn Association criteria for severe burn injury [36]. Patients were excluded from participation if they were unable to provide informed consent due to cognitive impairment, delirium, or psychotic disorder.

#### Procedure

The study was conducted with patients who were part of a larger multi-site study on recovery from burn injury. Only patients from the Johns Hopkins site were included in this study since no other sites administered the core measures at the time data was collected. In-hospital, participants either completed a packet of study questionnaires alone or with the help of the research assistant, if necessary. Patient demographic data and burn injury characteristics were recorded on a standardized data report. Participants completed follow-up measures at 6 and 12 months, either by phone or by filling out the packets at home and returning them by mail. All patients provided informed consent, and the Johns Hopkins University School of Medicine Institutional Review Board approved the study.

#### Measures

*Body image satisfaction.* Patients were administered the Satisfaction with Appearance Scale (SWAP) [37] to assess non-weight-related body image dissatisfaction. There are 14 items, which are on a 7-point Likert scale (0 to 6; *strongly disagree* to *strongly agree*). Respondents rate the degree to which the items describe their thoughts and feelings about their appearance since the burn injury (e.g., "I am satisfied with the appearance of my face"). The SWAP was scored so that higher scores represent greater dissatisfaction (range = 0 to 84). Good internal consistency has been reported for the SWAP total score among patients with burn injuries (Cronbach's alpha = .87) [37].

*Importance of Appearance.* The Importance of Appearance subscale of the Multidimensional Body-Self Relations Questionnaire (MBSRQ-IA) [38] was used to assess investment in and importance of physical appearance. The MBSRQ-IA was administered only in the hospital, and participants were asked to rate their behaviors prior to the burn injury. The MBSRQ-IA includes 12-items that measure investment in appearance (e.g. importance of one's looks, grooming behaviors). Items are scored 1-5 (*Definitely Disagree* to *Definitely Agree*). Higher scores reflect a greater investment in appearance (range = 12-60). Good internal consistency has been reported for the MBSRQ-IA for both women and men (Cronbach's alpha = .85 and .88, respectively) [38].

*Psychosocial functioning*. The Mental Composite Scale (MCS) of the SF-36 Health Survey [39] was used to assess participants' psychosocial functioning. In the hospital, participants were asked

to rate their behaviors preburn. Subsequent ratings assessed functioning at the time of the assessment. The SF-36 is a 36-item multi-purpose health survey, which yields an 8-subscale profile of functional health and well-being, as well as empirically-derived physical and mental health summary measures. The SF-36 is the most widely used and evaluated health outcomes measure and has extensive evidence for its validity and reliability in multiple populations [39,40].

#### **Data Analysis**

Only participants who completed the SWAP in-hospital and at 6 and 12 months were included in this study. To assess whether completers were different from patients who did not complete the study, participants who completed questionnaires in the hospital and at both 6 and 12 month follow-ups were compared to participants who did not complete all assessments. In addition, patients in the study were compared to all patients admitted to the Johns Hopkins Burn Center from 1995-2005 to assess the representativeness of the study sample in terms of age, sex, and burn injury. Categorical variables were assessed using the  $\chi^2$  statistic and continuous variables with 2-tailed *t* tests. To assess body image dissatisfaction across assessment periods, a repeated measures analysis of covariance (RM-ANCOVA) was used. The RM-ANCOVA model was also used to evaluate the relationship of body image dissatisfaction with sex, importance of appearance, and injury severity as measured by TBSA, as well as the differential impact of these variables across time. These analyses were conducted using SPSS version 14.0 (Chicago, IL), and all statistical tests were 2-sided with a *p* < .05 significance level.

Path analysis was used to test the role of body image dissatisfaction as a mediator of preburn psychosocial functioning and psychosocial functioning 12 months postburn. Sex, TBSA,

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and importance of appearance were also included in the model as predictors of body image dissatisfaction. The path model was carried out with EQS 6.1 [41] using maximum-likelihood estimation. Model fit was assessed with the chi-square statistic and three model fit indices: the Tucker-Lewis Index (TLI) [42], also known as the non-normed fit index (NNFI) [43], the comparative fit index (CFI) [44], and the root mean square error of approximation (RMSEA) [45]. Rough guidelines suggest that models with TLI/NNFI and CFI between .80 and .90 fit moderately well, with >.90 indicating a well-fitting model [45,46]. RMSEA values <.05 are considered to be representative of good fitting models, and values between .05 and .08 of moderate fit [46].

#### RESULTS

#### **Patient Characteristics**

The sample included 79 patients (of 209 in-hospital) who completed assessments inhospital and at 6 and 12 months. Sex, age, race/ethnicity, education level, and burn injury characteristics of participants in the final cohort were not significantly different from those of participants lost to follow-up. In addition, included patients were generally representative of burn patients admitted to the Johns Hopkins Burn Center. As shown in Table 1, the study sample was not significantly different from all admitted patients in terms of age, sex, and the percentage with a burn to the head and/or neck. Patients in the study, however, did have significantly larger TBSA burns than the sample of all admitted patients (p < .01), which is not surprising since the extent and location of the burn injury were study inclusion criteria.

#### **Course of Body Image Satisfaction**

The bivariate Pearson correlations with SWAP for in-hospital, 6 months, and 12 months were for TBSA, 0.16, 0.26, and 0.36; for sex, .13, .20, and .32; for importance of appearance, .31, .31, and .34. The mean score on the SWAP was 27.8 (SD = 15.5) in-hospital, 30.0 (SD =19.1) 6 months postburn, and 27.4 (SD = 17.2) 12 months postburn. In the RM-ANCOVA model, the main effect of time was not significant (F(2,150) = 1.42, MSE = 115.3, p = .25, partial  $\eta^2 = .02$ ). The main effect of sex (*F*(1,75) = 4.10, *MSE* = 2,096.0, *p* <.05, partial  $\eta^2 = .05$ ) and the covariates TBSA (F(1,75) = 12.72, MSE = 6,502.9, p < .01, partial  $\eta^2 = .15$ ) and importance of appearance (F(1,75) = 15.7, MSE = 8,026.1, p < .01, partial  $\eta^2 = .17$ ) were significant. The sex x time (F(2,150) = 6.52, MSE = 532.7, p < .01, partial  $\eta^2 = .08$ ) and TBSA x time interactions were also significant (F(2,150) = 8.88, MSE = 722.8, p < .01, partial  $\eta^2 = .11$ ). The importance of appearance x time interaction was not significant (F(2,150) = 2.55, MSE = 207.4, p = .08, partial $\eta^2 = .03$ ). As shown in Figure 1, body image dissatisfaction adjusted for TBSA and importance of appearance, increased among women across time, but decreased among men. To illustrate the TBSA x time interaction, estimated SWAP scores at the mean TBSA and one standard deviation above and below the mean TBSA were calculated with linear regression, using mean values for sex and importance of appearance. As shown in Figure 2, adjusted mean SWAP scores were similar in hospital for mean TBSA (27.8), low TBSA (25.7) and high TBSA (29.9). Burn survivors with small TBSA burns, however, improved substantially over time (mean SWAP at 12 months = 19.1), whereas those with large TBSA burns were increasingly dissatisfied with their body image (mean SWAP at 12 months = 35.6). The importance of appearance x time interaction is shown in Figure 3. Mauchly's test for non-sphericity (.95, p = .15) and the Greenhouse-Geisser estimate of epsilon (.95) did not suggest significant heterogeneity of

variances of difference scores across time. Nonetheless, data was reanalyzed using the conservative Greenhouse-Geisser adjustment, but no results changed.

#### Body Image Satisfaction as a Mediator of Preburn and 12-Month Psychosocial Function

Figure 4 shows the initial path model specification. The model tested the plausibility of the hypothesized role of body image dissatisfaction, measured at 12 months, as a mediator between preburn psychosocial function and 12-month psychosocial function. The model also included sex, TBSA, and importance of appearance as predictors of body image satisfaction and sex as a predictor of importance of appearance. The initial model provided a reasonably well-fitting representation of the data ( $\chi_8^2 = 14.1, p = .06$ ; CFI = .93, TLI/NNFI = .86, RMSEA = .11), and all hypothesized paths were significant. Sex, TBSA, importance of appearance, and preburn psychosocial function accounted for 40% of the variance in body image dissatisfaction. Body image dissatisfaction mediated the relationship between preburn psychosocial function and 12-month psychosocial function. Together, the variables in the model accounted for 44% of the variance in 12-month psychosocial function. Additional direct paths from TBSA and sex to postburn psychosocial function were tested posthoc, but were not significant.

#### DISCUSSION

The current study is unique in that it is the first to track changes in body image over the first year of recovery from a severe burn. Both Thompson and Partridge, leading theorists on the process of adjusting to acquired disfigurement, have posited a staged process of adapting to unexpected alterations in one's appearance. Particularly relevant to the current study, Thompson and Partidge's respective models suggest that people with acquired disfigurement will go through

an initial developmental period in which body image will worsen over time as the person struggles to accept physical changes that are out of his /her control and develop the social skills necessary to cope with newly experienced social stigmatization. The current study lends qualified support to the hypothesized adjustment period. For both women and those with larger TBSA, body image dissatisfaction increased over time as reflected in the significant interactions between sex and TBSA and time, respectively, in the RM-ANCOVA model. In contrast, importance of appearance had a relatively strong consistent relationship with body image at all three time points.

We can speculate about the reason why importance of appearance affected the course of adjusting to body images changes differently than either TBSA or sex. Perhaps, for those who highly value their personal appearance, a threat to their appearance is emotionally salient immediately from impact of the initial injury. For others, the ramifications of a changed appearance are consolidated with experienced over time. In addition, it is to be expected that the impact of an altered appearance on a burn survivor's social life will be greater for women than men and for those with a larger TBSA. In general appearance standards in North American culture are stricter for women than men and consequently women tend to have lower body image [47, 48]. In regards to TBSA, in previous studies in which body image measures have been collected at one time point among people with acquired disfigurement, severity of disfigurement tended to have a modest relationship with body image [12, 13, 49, 50]. This study showed that it is important to consider when this relationship is assessed as the magnitude changes substantially over time.

The second major finding in this study was that body image mediated the relationship between preburn psychosocial functioning and postburn psychosocial functioning. This suggests that adjusting to appearance changes is an integral part of adapting after a severe burn. The model is consistent with a recent survey of 458 adults with a variety of disfiguring conditions in England many of whom reported experiencing stigmatizing behavior and distress related to adjusting to being visibly different [10].

Social interaction skills training programs [51,52] and cognitive-behavioral therapy for social anxiety [22] have been recommended for patients with disfigurement. Social interaction skills training programs are based on the premise that a negative feedback loop increases social isolation among people with disfigurement. Based on experiences of being the recipient of unwanted negative attention and/or an understanding of cultural biases related to appearance, individuals with disfiguring injuries anticipate negative reactions from others. In doing so, they may behave defensively or display avoidant or aggressive behaviors, which, in turn, elicits negative behavior from others and reinforces their perception that they are perceived negatively by others. Consistent with this, a recent study by Hagedoorn and Molleman [25] demonstrated that the association between degree of facial disfigurement among patients with head and neck cancer and psychological distress is mediated by self-efficacy, defined as the extent to which patients believe that they are capable of influencing the reactions and openness of others.

Social skills training programs seek to teach people with disfigurement to effectively anticipate and manage the reactions of others, resulting in positive feedback and increased selfesteem and confidence [51]. *Changing Faces* has offered workshops on social interaction skills for adults with facial disfigurement since 1992 [51]. Robinson et al. [51] reported that

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participation in a 2-day *Changing Faces* workshop was associated with improved overall anxiety and social anxiety 6 months later among 64 patients with a variety of types of facial disfigurement, although there was no control group. Recently, Blakeney et al. [53] adapted the *Changing Faces* workshop social skills curriculum to develop a 4-day workshop program for adolescent burn survivors who had been burned at least 2 years previously. Adolescents who attended the workshop program showed somewhat more improvement one year later in behavioral and emotional variables compared to a control group.

Cognitive-behavioral approaches are similar in some ways to social skills training approaches, but place more emphasis on the notion that the difficulties of people with disfigurement in social situations are maintained by fear of these situations and utilize exposure and response prevention paradigms common to treatments for social anxiety [54]. Newell and Clarke [54] found that a self-help leaflet that described cognitive-behavioral strategies for coping with social anxiety related to body image resulted in improvement in symptoms of anxiety and depression among individuals with disfigurement compared to a control group 3 months after the intervention.

No intervention related to body image or disfigurement has been specifically tested with adult burn survivors. Partridge has suggested that social interaction skills training should be provided for patients with burn injury prior to discharge from the hospital so that they can better anticipate potential problems and acquire methods for managing them. He has also recommended that skills be made available to non-disfigured family members and relevant others (e.g., classmates or co-workers) so that they are equipped with the social tools necessary to accommodate and interact with people with disfigurement. Parents and families may not

always know how to be of support in the recovery process, and others may avoid interactions due to uncertainty about how to react to disfigurement [34]. Future research is needed to test whether social interaction skills training or other cognitive-behavioral interventions might help to attenuate the upswing in body image dissatisfaction and overall worsening of psychosocial function experienced by many adult burn survivors after discharge from the hospital. Specifically, studies should investigate the type of advice or training that should be provided and how and by whom interventions should be delivered. In addition, research should evaluate whether extended skills training that involves family members or others is effective.

The findings from this study should be interpreted in the context of its limitations. Although the study sample was generally representative of patients admitted to the burn center, it was a very small sample that did not allow investigation of more complex relationships among variables, such as interactions [20]. More than half of the patients sampled during their hospitalization were lost to follow-up. This is typical in longitudinal studies of patients with burn injuries, and patients included in the study did not differ significantly from those lost to follow-up. Nonetheless, this might have introduced unknown biases. Sample-size limitations did not allow for more sophisticated analytical methods, such as individual growth curves in the context of hierarchical linear modeling. Other limitations include the use of self-report data for both independent and dependent variables, the use of retrospective assessment of preburn function and importance of appearance, and the lack of a strong existing theoretical framework for selection of model variables. Furthermore, the measures included in the study did not allow us to test for qualitative changes in body image over time, to assess the importance of severity and/or visibility of scarring, or to assess psychosocial functioning on a more complex level than permitted by the SF-36 mental composite score. An additional limitation of this study that is common among studies of burn survivors is that there were only a handful of patients in the sample with very large burns (e.g., TBSA >50%). The findings of this study may not represent the experiences of these patients very well, and the results of the study may underestimate the strength of the relationship between burn severity and psychosocial processes and outcomes. Finally, the follow-up period in this study was relatively short. Body image dissatisfaction is a salient stressor many years after a burn injury [11,12,27], but little is known about its course or longitudinal relationship with important outcomes, such as depression.

Due to these limitations, this study needs to be replicated. Nonetheless, the results provide a preliminary confirmation of Partridge's conceptualization of the challenges faced by burn survivors in recovery and suggest that screening for body image distress is an important consideration for burn survivors, both in the hospital and after discharge. Additionally, the findings indicate that the extent of the burn injury, female gender, and subjective importance of appearance may be risk factors for developing body image dissatisfaction post-burn injury. Currently, psychosocial interventions lag far behind medical interventions for survivors of burn injuries. In recent decades, the proportion of patients who survive large burn injuries has increased dramatically due to the development of comprehensive burn centers and improvements in treatments [55,56]. Surviving a massive burn, however, typically comes with extensive scarring and profound social challenges. Little has been done to systematically address these challenges among adult burn survivors. It is hoped that the findings from this study will lead to focused systematic research of interventions for body image distress and related social anxiety for this group of patients and, clinically, to the more systematic identification of patients who are at risk for body image distress and social anxiety. Following patients long-term for psychological care, in addition to medical complications, may create an opportunity to improve overall burn care and recovery, as well as an opportunity to address a burdensome condition that has been related to increased risk of depression and ongoing social difficulties among adult burn survivors [27,28].

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Table 1. Demographic and Burn Injury Characteristics of Study Sample Compared to All

	Study Sample (N = 79)		Johns Hopkins Burn Center (N = 2,657)		Significance
	n	%	n	%	р
Male	55	69.6	1875	70.6	.86
White	54	68.4			
High School or More Education	59	74.7			
Married or Living with Partner	32	40.5			
Burn to Head/Neck	28	35.4	930	35.0	.94
	Mean	SD	Mean	SD	р
Age [years]	41.7	15.5	44.7	17.3	.13
TBSA Burned	16.0	15.5	10.5	16.7	<.01

Patients Admitted to the Johns Hopkins Burn Center 1995-2005

# FIGURE 1.



Time of Assessment

# FIGURE 2.



# FIGURE 3



### FIGURE 4.



### **FIGURE LEGENDS**

- Figure 1. Mean SWAP scores for men and women in-hospital and at 6 and 12 months postburn, controlling for TBSA and importance of appearance. The mean score for women is represented by the solid line and for men by the dashed line.
- Figure 2. Mean SWAP scores for participants with low (1 *SD* below mean), mean, and high (1 *SD* above mean) TBSA in-hospital and at 6 and 12 months postburn, controlling for sex and importance of appearance. The mean score for patients with low TBSA is depicted by the line composed of long dashes, for patients with mean TBSA by the solid black line, and for patients with high TBSA by the line composed of short dashes.
- Figure 3. SWAP scores for participants with low (1 *SD* below mean), mean, and high (1 *SD* above mean) importance of appearance in-hospital and at 6 and 12 months postburn, controlling for sex and TBSA. The mean score for patients with low importance of appearance is depicted by the line composed of long dashes, for patients with mean importance of appearance by the solid black line, and for patients with high importance of appearance by the line composed of short dashes.
- Figure 4. Path model specification with parameter estimates. Numbers printed next to single-headed arrows correspond to standardized regression weights. All regression weights are statistically significant (p < .01).